

EXECUTIVE SUMMARY

MAY  
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# Children to Adult Mental Health Transition Research 'The Young People's Voice'

Angie Felkin Heins Participation Development Lead

(SPARK) Maindy Road, Cardiff, CF24 4HQ  
029 2039 6974 • [admin@tgpcymru.org.uk](mailto:admin@tgpcymru.org.uk)

On request this information will be available in different languages and formats.  
Please contact: [communications@tgpcymru.org.uk](mailto:communications@tgpcymru.org.uk).

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## Summary

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**In January 2022 TGP Cymru, a leading independent Welsh charity working with some of the most vulnerable and marginalised children, young people and families in Wales, were contracted by the Welsh Government to research the experiences of young people transitioning from children to adult Mental Health Services. This included all the young people that were in the transition process, those who had transitioned and those young people that have tried to move on to adult services but had not met the mental health criteria of severity or condition.**

There have been many research papers published about the issues that young people encounter while transitioning from children to adult mental health services, but this is a report that tells their story in their own words. It recounts the issues they faced, but also what they would like to see happen to help this process be more effective in helping young people move forward.

The priority issues in this Report were captured through a bilingual online survey, questionnaires, face-to-face and virtual group work to understand and establish what transition support solutions they would value.

This research would not have been possible without the cooperation of statutory and charitable youth organisations across Wales. Together we have been able to reach out to the young people of Wales and ask them to share their experiences and voice their concerns and opportunities for improvement.

The Welsh Government transitions guidance was published just before we carried out this research in February 2022 and the young people's version was used with the young people taking part to reflect upon their own experiences against the standards set.



## Research Overview

This research study was initiated to hear the experiences of young people transitioning from children to adults Mental Health Services. The questions asked were:

- Please tell us about your positive experiences of being supported by CAMHS and/or AMHS e.g. support from workers, any specific resources used, different ways of working etc.
- Please tell us about anything you think could be improved e.g. support from workers, any specific resources used, different ways of working etc.
- Please look at the link below about what should happen when a child transitions to adult services and comment on whether it reflects your own experience e.g. having a named worker and a transition plan
- Is there anything else you can identify that is missing?
- Please look at the link below – is this the care and treatment plan you have used? and do you think it is fit for purpose
- The link below shows an example of a ‘Young Person’s Passport’ – A document that holds all the relevant information about you that you can use with professionals, so you don't have to keep retelling your story? Please comment on whether you think this is a good resource to use.
- Do you think an app, like the one in the link below, would be useful and would you use it? This is the app that’s used to help young people manage their diabetes. It holds all the information the young person needs as well as resources and information.
- What else would be popular for young people to help support their own mental resilience e.g. e-learning workshops, online/face-to-face support groups, online/face-to-face well-being sessions etc. Is there anything already available that you think is, or would be good?

## Strengths and Limitations

Participation in this research was totally voluntary and engaging young people that had experience of the transition process from CAMHS to AMHS; whether they were in the transition process, had transitioned or had tried to move on to adult services, meant that the target group was very small. There was also the additional limitation that these young people often do not want to engage due to their mental health issue. This mirrors the limitations that Mind Cymru encountered in their recent 2022 report ‘Sort the Switch’ (2022:20) Many of the young people that did respond were from the ‘seldom heard of group’, e.g. care experienced and young carers, and so it was important to capture their voices and report on them.

24 young people attended the workshops or completed the questionnaire and 83% of them had CAMHS experience. Of the 30 young people who responded to the bilingual online survey 40% had experience with CAMHS. Of these young people 45% from the workshops and 25% from the survey had transitioned to AMHS or were waiting for the transition. . These 12 young people answered questions about the specifics of transitioning, but all 54 young people, aged 13 to 25 years , were asked to complete questions about tools and resources that could help young people with transitioning and during their mental health challenges. The young people who responded were from across the whole of Wales.

**Mind Cymru (2022) Sort the Switch: The experiences of young people moving from Specialist Child and Adolescent Mental Health Services to Adult Mental Health Services in Wales. Cardiff: Wales. Available at: [www.mind.org.uk](http://www.mind.org.uk)**

**TGP Cymru Children to Adults Mental Health Transition Research  
Angie Felkin-Heins – Participation Development Lead**

## Research Survey Findings

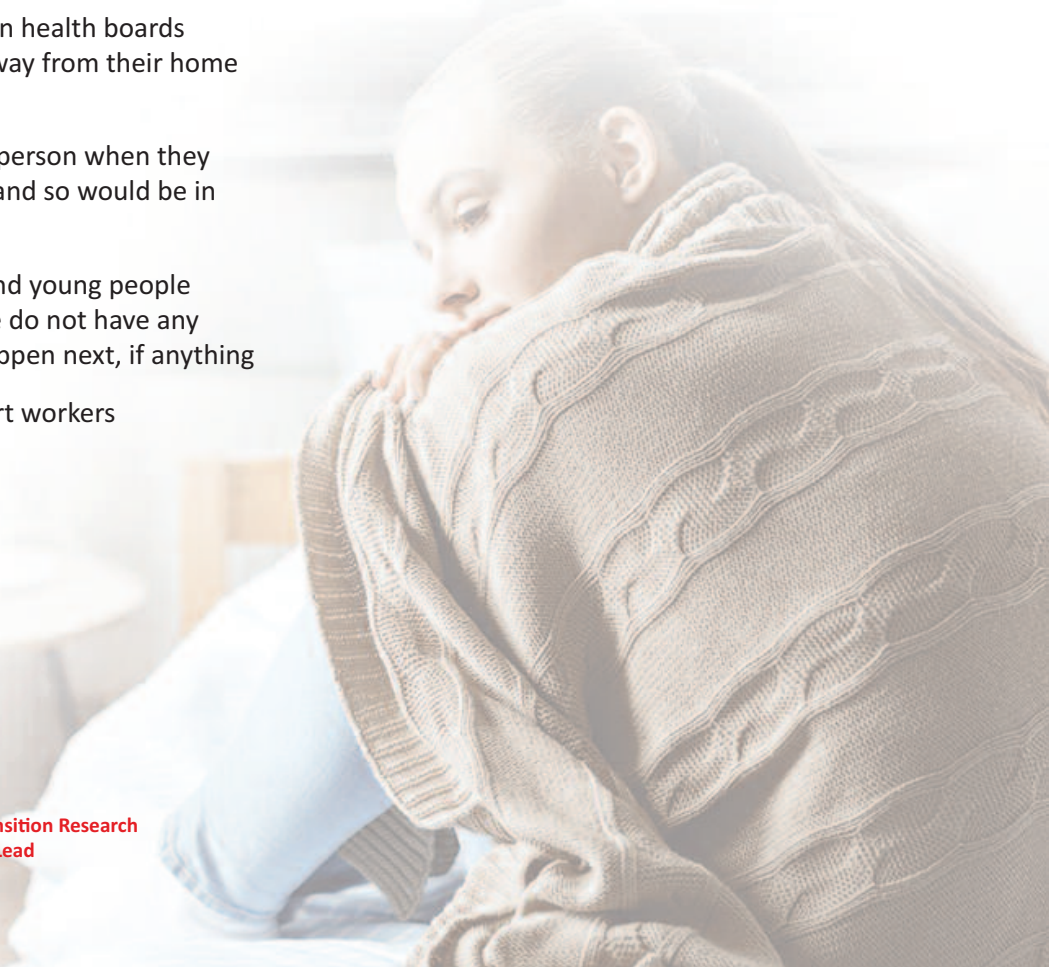
### Positive Experiences of being supported by CAMHS and/or AMHS

Unfortunately, this was the most disappointing response in the research as young people found it difficult to articulate what in their experiences had been positive.

### What Could Be Improved?

From the comments of young people these were the main themes that were identified:

- **Getting referred**
  - Lack of information about how to move to adult services
  - Being told their mental health issue was not severe enough to move
  - Issues connected with moving away from home for work or university and so changing GP's
  - Treatments finishing as soon as you are 18 years old without a follow-on plan
  - Being discharged for not engaging when correspondence has not been received
- **Support while waiting to be referred**
  - Lack of communication between health boards when a young person moves away from their home for work or university
  - GP's reluctant to refer a young person when they are coming up to 18 years old and so would be in the transition phase
  - Waiting lists are long anyway and young people coming up to adult services age do not have any information about what will happen next, if anything
  - Lack of consistency with support workers
- **The consultation experiences**
  - Having to keep retelling your story
  - Suggesting different treatments rather than just medication
  - Not using the same 'go-to' treatments all the time even if they did not work for the individual before
  - Having more face-to-face time
  - Worker's lack of empathy
  - Not feeling they were being seen as individuals
  - Not feeling comfortable
  - Not feeling involved in their consultations
  - Not feeling in control and not listened to



## Experiences in relation to the Welsh Government Transition and Handover Guidance

We asked the young people that had been involved in the transition process whether they had experienced any of the good practice guidance outlined in the young person's version of the transition from children to adult healthcare services guidance. This included early planning, a named support worker chosen by the young person and a transition plan, or young person's passport.

Young people expressed that they had not had transition or handover plans or named support workers of their choosing. Some young people said there was not any planning they were just told they were either moving to adult services just before they did, or they were just dropped without any explanation before they moved.

We shared a link with the young people to the care and treatment plan that is used and asked them if they thought it was fit for purpose. Apart from one 18 year old young woman from north Wales who confirmed, in the survey, that they had seen it and thought it was fit for purpose, none of the other young people asked were even sure what a care plan was.

### Have you seen the 'Young Person's Passport' and do you think it is a good idea?

When we asked the young people if they had seen the 'Young Person's Passport' most of them had not seen it. The young people in the workshops were then shown two different young person's passports. The resource attached to the

Welsh Government 'Transition and handover from children to adult health services' February 2022 Annex 4 (2022:33-46) they thought was really long and felt that they would not want to complete it. They also thought it was quite childish for their age group and not appropriate to young people moving to adult services. The other resource was the NHS England Children & Young Person's Mental Health Service Information Passport - illustrated example and this example they believed was more appropriate and 87% of the survey and 88% of the workshop of the young people thought it was a great idea.

### Do you think an app would be useful and would you use it?

The young people were shown an example of an app that could be used to hold all the information the young people would need as well as resources and information to support them. The example of the app used was to help young people manage their diabetes. The 84% of the survey and 96% of the workshop young people really liked the idea of this and also had some suggestions on how to make it more supportive for young people.

The Transition and Handover Guidance\_February 2022 (gov.wales)

cyp-info-passport-yp-example.pdf (england.nhs.uk)

[www.digibete.org/digibete-app/](http://www.digibete.org/digibete-app/)

## What else would be good for young people to help support their own mental resilience?

At the end of the survey and the workshops the young people were asked if they had any suggestions of things that young people could do to help their own mental health and they were forthcoming with many suggestions. The most popular were face-to-face support groups and wellbeing sessions but there was also some support for these also being available online, or even being a blended approach so you can join the group whichever way you feel most comfortable. The young people also identified many apps they already use and also people and groups that they work with that have had a positive effect on their mental health.

## Conclusion and Recommendations

At the end of the survey and the workshops the young people were asked if they had any suggestions of things that young people could do to help their own mental health and they were forthcoming with many suggestions. The most popular were face-to-face support groups and wellbeing sessions but there was also some support for these also being available online, or even being a blended approach so you can join the group whichever way you feel most comfortable. The young people also identified many apps they already use and also people and groups that they work with that have had a positive effect on their mental health.

The young people that chose to be involved in this research have given clear indications of where the transition process from children to adult mental health services is failing young people. There is sufficient evidence that this failure has been taking place for a number of years even though reports and guidance has been published since 2015. Some consideration needs to be given to the fact that the Covid 19 pandemic did have an effect on the delays in seeing young people and in continuing their support, but the problems around the transition process were there well in advance of this.

There have been some positive reports from young people about their experiences with children and adult mental health services and we need to consider that the young people who chose to take part in this research were one's who had had issues. The interesting revelation during this inquiry though has been that even though the age group we advertised to were 15 years and older a lot of young people under this age wanted to have their voices heard as the issues seem to be presenting themselves at an earlier age and they are concerned what will happen in the future.

The main issues identified were about the difficulties of being referred to adult services, the lack of support while waiting and the consultation experience where they felt little or no control. The guidance though has been available for a long time and the young people have clearly shown that if it was implemented it would make a real difference. They also think the young person's passport is something they would use, even though they have chosen a different format to the one chosen by the Welsh Government. They are aware that the process also needs to be individualised as a transition at 18 years is not an age that suits everyone's mental health needs and they need to be involved in their care and treatment plan. Young people think that an app, like the diabetes app, would be a great idea and they need to be involved in its development as they have some great ideas to make it a really effective resource. The young people have shown that they have used lots of different ways to help themselves and are proactive in finding these, but they need to know that when they cannot there is a service there that can support them in an efficient and timely way.

## Recommendations

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- 1** Young people need the information about the how, who and what happens next when it comes to transitioning from children to adult services. There needs to be a handover and transition guidance developed that is especially for mental health services and this needs to be implemented, including that young people need to be involved in their own care and treatment plan.
- 2** The young person's passport needs to be redesigned to be more like the NHS England passport, shorter and easier to complete. This needs to be done through consultation with the young people who will use it and then implemented and used throughout Wales so young people do not have to go through the trauma of continually retelling their experiences to different people.
- 3** Design an app, similar to the diabetes app, through consultation with the young people who will use it and then be made available to support all young people that need it.
- 4** As youth forums across Wales have wellbeing and mental health issues at the top of their agendas, there needs to be a good network of face-to-face and online support groups across Wales. The youth organisations that have these already should have support to continue to deliver these.
- 5** Throughout this research young people have been asked if they want to be a part of a follow up group that sees that the recommendations are followed through. I would like these young people to be invited to discuss these with the Welsh Government, either in person or through a virtual forum, and be kept up to date with all developments.

**For any questions or further detail on the findings, please contact:  
Angela Felkin-Heins, TGP Cymru Participation Development lead  
[getinvolved@tgpcymru.org.uk](mailto:getinvolved@tgpcymru.org.uk)**



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(SPARK) Maindy Road, Cardiff, CF24 4HQ  
029 2039 6974 • [admin@tgpcymru.org.uk](mailto:admin@tgpcymru.org.uk)